

Ending a Life in the Beginning: An Informative Analysis of Pediatric End-of-Life Palliative  
Care

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### An Introduction to Palliative Care

After months and years of loving, caring, worrying, and anticipating the arrival of a new life, how can one decide to end that young life just as quickly as it arrived? This is the dilemma some families are forced to face when they have a child with life-ending complications. Is it fair to out live one's child? Is it fair to play God and decide to end that child's life? These questions are only a few questions families are forced to face. Behind all of these questions, however, lie the deeper issues of morality and ethicality.

Addressing morality and ethical elements are often focused on in end-of-life care. This is especially true when the life that is ending is that of a child. To end a life that has yet to flourish forces one to face morality and question its ethical acceptability. Palliative care nursing helps one face these issues. Palliative care is a specific area of nursing that focuses on providing holistic comfort to those in the end stages of life, while maintaining ethically acceptable care (American Academy of Pediatrics [AAP], 2000). Choosing to provide palliative care is not an easy decision, especially when the patient is a child. The purpose of this paper is to examine the ethical involvement in pediatric palliative care. This is an important issue because providing ethically sound care is a priority in the nursing profession.

### The Decision Process

A family's decision to change the plan of care from curative to palliative care can be the most difficult decision that family makes. This decision comes after an emotional rollercoaster of highs and lows full of uncertainty the family has already had to endure (Romesberg, 2007). Parents, mothers in particular, often face an ethical dilemma regarding their obligations to care

for their seriously ill child (Corkin, Price & Gillespie, 2006). Their first reaction is to do anything to make their child live, "...we didn't care, we just wanted her to live...I was determined that my daughter would not die." (Berg, 2006, p. 239). However, this attitude can only last for so long. When one begins to see the suffering, pain, and discomfort their child is facing just to live, the attitude often changes. Hannan & Gibson (2005) reported that parents of seriously ill children with incurable diseases change their attitude in the plan of care, leading them to seek palliative care. The reason behind this change is the parent's wishes to provide continual comfort care for their child, while allowing them to enjoy & value the little time they have left with them. The ethical dilemma however, arises with this new plan of care due to the inevitable loss of their child's life. For that reason, reaching this final decision is a long and heartbreaking process. As commented by one mother;

"If clinicians think that parents can be presented information just once about life or death decisions and then expect parents to say "yes" or "no," it won't happen. As a parent, this type of decision is an evolving process. You need to be presented with information compassionately, have a chance to ask questions, then develop your thinking as a parent..." (Dokken, 2006, p. 175).

To make this life ending decision, parents must be well informed, have compassionate caregivers, and trust those involved in the care of their child (Dokken, 2006).

### Goals and Principles of Palliative Care

Caring for a child is the primary goal in any pediatric nursing care. However, when the focus of care is palliative, the outcomes in the plan of care are augmented. The goal of palliative care is care focused on alleviating symptoms without curing (Romesberg, 2007). As supported by the American Academy of Pediatrics, to provide this type of care and accomplish the goal ethically, certain principles are necessary (AAP, 2000). These principles include respect for the

dignity of patients & families, access to competent & compassionate palliative care, and support for the caregivers (AAP, 2000).

Respect for the dignity of the patient & family is the cornerstone principle in providing ethically sound palliative care (AAP, 2000). Without respect, the basic Standard of Care for nursing is being breached therefore; ethically, the care given cannot be described as ethically acceptable, and the goal of palliative care cannot be met.

Access to competent & compassionate palliative care is another keystone principle necessary in providing ethically acceptable care. Included in this are various therapies such as, “education, grief & family counseling, peer support, music therapy, child life intervention or spiritual support for parents & siblings, and appropriate respite care” (AAP, 2000, p. 351). By providing such therapies, it allows families time to absorb the situation at hand, coordinate care necessary for the patient, prepare for the future, and maintain a quality of life as close to normal as possible (Institute of Medicine of the National Academies, 2002).

The final principle necessary in accomplishing the goals for providing ethically acceptable palliative care is support for the caregivers (AAP, 2000). Parents and family members are not the only ones involved in the care of the patient. Most of the nurses that care for these palliative care patients develop a special bond with them, and as a result, they too need support just like the family. These health care professionals require support from their colleagues, institutions, and other health care providers (AAP, 2000). This is so that the providers can provide proper care for their patients, without breaking down themselves, physically and emotionally. Together, all of these principles help accomplish the goal of pediatric palliative care.

### Barriers Nurses Face

Understanding the necessary principles for palliative care may be easy to comprehend, however providing the actual care can be difficult due to barriers nurses face. Many undergraduate programs lack the proper environment and necessary preparations needed to help teach their students how to provide optimum palliative care for their pediatric patients (Malloy, Ferrel, Virani, Wilson & Uman, 2006). This lack of proper training has lead nurses to many barriers in providing proper care, which forces them into many ethical dilemmas (Malloy et al., 2006). These ethical dilemmas and barriers are the components that have made pediatric palliative end of life care an ethical issue today. Barriers nurses are facing in providing ethical care vary from personal morals, values & emotions, practicing beneficence & nonmaleficence, nurse exposure to death & stress, and grief (Kain, 2006).

In the beginning of one's career, nurses are encouraged to develop their own personal morals, values, and emotional coping mechanisms. The hope is that by doing so, it will help nurses cope with the death of pediatric patients in their own way. The issue however, is that no matter how comfortable one is with their morals, values, and coping mechanisms, providing any type of pediatric palliative end-of-life care leads to a negative experience for the nurse (Kain, 2006). The care provided still leads to the death of a child, which by societal norms is "unnatural", making it more difficult to understand (Kain, 2006). With this known negative experience, nurses are led to question whether they should or should not provide pediatric palliative care, given the possibility that the evolving modern technology may someday provide a solution to allow the child to live.

Practicing beneficence & nonmaleficence also is cited as a barrier to providing ethical pediatric palliative care (Kain, 2006). Defined, nonmaleficence is the requirement to "do no

harm”, while beneficence is not only the preservation of life, but also understanding that preserving life is not always in the best interest of the patient if the quality of life suffers (AAP, 2000). These principles often come in conflict in regards to dying children and pain. Pediatric palliative care nurses face a moral dilemma when they deal with this situation of inflicting pain; does the “potential of maleficence outweigh beneficence” if quality of life suffers in the situation at hand (Kain, 2006, p. 389)?

Another barrier is the nurse’s exposure to death (AAP, 2000). With cumulative exposure to pediatric death, nurses are more vulnerable to anxiety and trauma, making them “psychologically unable to support dying babies and their families” (Kain, 2006, p. 389). In addition, the continuing exposure to death is personally emotionally difficult for the nurse causing distress that cannot be avoided, which leads to an increase in stress (Romesberg, 2007). If one is stressed and unable to support one’s patients, how can they focus and provide proper ethically sound care?

The final barrier is grief (Kain, 2006). Grief experienced by pediatric palliative care nurses is complex, especially if they were not prepared for the death and if there was pain & anguish during the death of the patient (Romesberg, 2007). In particular, it is known that the death of a child causes “more intense and complicated feeling than that of an adult” due to the unnatural event of a young life being lost (Kain, 2006, p. 390). In addition to these feelings of grief, pediatric palliative care nurses are prone to additional distress due to the training they received. Nursing is geared towards helping cure a patient in distress therefore; death of a patient may be viewed as a failure (Romesberg, 2007). The grief and emotional distress due to experiencing repeated deaths of children can lead to guilt and times of depression. This can lead to a nurse encountering personal psychological issues. Can this nurse adequately provide

ethically sound-nursing care when he or she is actually harboring unresolved grief himself or herself?

### A Final Thought

From these cited barriers, providing ethically sound pediatric palliative care can be difficult to accomplish. However, the need for pediatric palliative care is essential, and for that reason, these barriers should not get in the way of providing the care needed. Pediatric palliative care is a special field of nursing, and as with other fields, ethical dilemmas will arise. It is one's job as a nurse to critically think through each situation and reason the ethically appropriate way of providing care. After all, it is the innocence and vulnerability of a child the pediatric nurse is trying to preserve; while it is the holistic comfort to those innocent and vulnerable children the pediatric palliative care nurse is trying to provide.

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